

Working Group to Develop a State Plan for Alzheimer's Disease and Related Disorders

Research Subgroup

January 10, 2013

CORO West, Suite 304 A

Present: Peter Snyder (Lifespan), Brian Ott (RIH), Ana Tuya Fulton (Butler), Leslie Fontana (RISD), Nasser Zawia (URI), Lindsay McAllister (Lt. Governor Roberts).

1. Review and Approve Minutes from December 5th Meeting
 - a. Meeting minutes were approved without objections or changes.
2. Design Principles for a State-Based Research & Resources Website
 - a. Leslie Fontana, Professor, Department of Industrial Design at RISD, presented slides (available upon request) of the strengths of web resources already in our environment which the subgroup might refer to as it develops recommendations for a future alzheimer's-related web-based resource for the state.
 - b. The group then discussed the feasibility of such a resource in RI: where would it "live" and where would the resources come from to maintain it?
 - c. URI's Geriatric Education Center was discussed as a possibility.
 - d. Would each entity wishing to offer content "own" their portal to the website? Are there student's in the graduate programs who could fill this roll?
 - e. Content for the site would include: awareness of meetings and opportunities for support/services, clinical trials, new knowledge from research/clinical trials, a patient registry, blog ability for researchers to disseminate new findings and articles, etc.
3. *Handout* – Subgroup participant edits to National Plan to Address Alzheimer's Disease (NAPA) and the Vermont State Plan
 - a. Available upon request.
4. Building a Patient Registry & Upcoming Subgroup Agenda Items were addressed together.

- a. Future meetings will entail a representative from the state to assist the subgroup in understanding what data resources are already collected by the state and potentially available for research purposes.
 - b. The Subgroup also discussed bringing Thomas Anders in to discuss the development of RICART (the RI autism registry).
 - c. Lindsay McAllister shared an overview of the RIAPCD, explaining that this will be a claims based resource available in the near future, but it was unclear what data in the APCD would be sought after for dementia research.
 - d. Dr. Snyder will bring a fellow working on the architecture and design of a future patient registry to discuss the goals of such a resource.
 - e. These two items will inform the committee's work to form a more specific recommendation to the full group to include in the state plan: do we still need a specific alzheimer's/dementia patient registry given what is already available and able to be parsed out from the state? If so, can we meet the needs (design and architecture) envisioned by those who have been working on a registry by relying on state data?
5. The meeting was Adjourned at 5:44 pm.